Consumer Advisory Group Meeting
February 26, 2013 10:00-11:30a

Name	Organization
Kathleen Donaher	Regis College of Nursing
Eileen Elias	
Lisa Fenichel	
Barbara Popper	Federation for Children with Special Needs
Lucilia Prates	Massachusetts Senior Medicare Patrol (SMP) Program/Elder Services of the Merrimack Valley
Winnie Tobin	Medically Induced Trauma Support Services
Alec Ziss	CapeCare
Support Staff:	
Micky Tripathi	MAeHC
Mark Belanger	MAeHC
Erich Schatzlein	MAeHC
Carol Jeffery	MAeHC

Summary of Input and Feedback from the Consumer Advisory Group

- A technical change should be made to add a consumer representative to the HIT Council
- Consumers should be informed of Mass HIway plans as soon as possible – Advisory Group members can support outreach efforts
- Mass HIway should publicly post a list of providers who are connected to the Mass HIway so that consumers may choose a provider based upon this information
- Pros and cons for key decisions should be defined so stakeholders may weigh tradeoffs
- Project leaders should balance deployment speed with stakeholder input gathering efforts – there is a need to let patients into the conversation in a real way, elicit feedback, incorporate suggestions, and build trust
- A new shared understanding of consent needs to be cultivated given that the concept has evolved a lot since originally conceived in earlier Massachusetts HIE planning efforts
- Presentations should be updated to be patient centric
- Suggest using a tiered consent model that allows full access for ED providers
- Suggest that FAQs and patient education materials continue to be reviewed by the Consumer Advisory Group – specifically the FAQs that originated with the Consumer Work Group and that are being finalized by MeHI

Review of Materials and Discussion

- The group was welcomed back from a brief meeting hiatus and reviewed the distributed materials for the Advisory Group kickoff.

- The changes for 2013, under the MA Law Chapter 224, were reviewed and the structure detail of the new HIT Council and the Advisory Groups was discussed. (Slides 2-4)
    - The Advisory Groups will mirror the structure of Federal Advisory Committees and will focus on targeted issue areas. Existing volunteers from previous workgroups have been invited to participate in the Advisory Groups; membership is fluid and recruiting additional members was encouraged.
    - The purpose and objectives of the new Advisory Group will provide advice and expert opinion to the HIT Council
- The group reviewed the HIway phasing and strategy. (Slides 6-8)
    - Phase 1: Send and Receive – live since October 2012, allows the HIway to be available to all health care organizations in the State regardless of the technology in their respective offices. Phase 1 stood up the initial provider directory and associated technical components for participating organizations to send and receive messages. EOHHS and the Last Mile Program will focus on HIway operations and deployment of the HIway to health care organizations.
    - Phase 2: Search and Retrieve – creating the capability for cross-institutional queries and retrieval of patient records. Phase 2 requires detailed planning and will be the focus of this Advisory Group.
    - Comment: If providers/organizations do not participate in Phase 2, this will defeat the purpose or greatly diminish the value of the Mass HIway.
    - Comment: A great majority of the discussion points during the Consumer Advisory Group seem to be targeted toward a provider perspective. The discussion should be more focused in the direction of the consumer in order for the consumers to be more equipped in making an informed decision about participating or consenting to have their information shared on the HIway.
    - Comment: The group agreed in looking forward to producing, or having input toward production of, education materials geared toward consumers.
    - Comment: There has been a lack of input into and feedback on the FAQs previously worked on in the Consumer Work Group. This group would like to know the status of the FAQs and if they have been published in some form.
    - Comment: The MAeHC Quality Data Center (QDC) was noted as an example of an interface using the LAND device to connect to the Mass HIway (and the nuances needed per installation to achieve this connectivity). A question was raised regarding the data received by the QDC which is not de-identified data.
        - Answer: This data is secure and is not shared with any other organizations or individuals and is being compiled for the benefit of the organization providing the data. In order to target quality improvement measures for a provider or organization, the patient data must be identifiable.
    - Question: Will any activity linked with Medicaid be subject to the impact of sequestration which will in turn impact the Mass HIway plans?

- The three methods to connect to the Mass HIway were reviewed with a highlight to the additional features of Phase 2 added to the HIway service options. The group was reminded that Phase 2 services are not a requirement for participation in the Mass HIway. While there is an additional fee for HIway Phase 2 services, the features and functions of Phase 2 will benefit any organization in their healthcare operations. (Slide 10)
- The group discussed the components of the HIway Phase 2. (Slide 11)
    - The Master Person Index (MPI) offers probabilistic patient matching, direct matches only, utilizing the Orion Initiate system. "Wildcard" or "fishing" searches will not be allowed.
    - The Consent database is actually part of the Master Person Index (MPI) but is depicted separately for discussion purposes. A patient consent is captured at the organization level and the consent status is sent to the Mass HIway.
        - Most EHR (electronic health record) systems are not sophisticated in their ability to capture and react to patient consent. EHRs are limited in consent capture; it's a 'yes' or 'no' only without restrictions about what data will be shared by the EHR. Consent will be a topic for a future Advisory Group meeting.
    - The Record Locator Service (RLS) only shows those organizations that a patient has authorized (consented) to respond to queries. The method used to respond to a query will be a decision made at each individual organization.
    - Question: Will organizations be required to provide patient demographics to the Master Person Index (MPI) in order to participate in Phase 2?
- The query/retrieve methods for Phase 2 services were reviewed. (Slide 12)
    - Cross-entity viewing from one EHR into another EHR. This approach is used by some MA healthcare organizations today using "magic button" technology which allows an authorized provider to view the record of a patient from another organization's EHR.
    - Push/Push offers email-like functionality and does not require new technical solutions. This method will necessitate a manual workflow process at either end of the transaction but does not require new standards definitions and leverages Meaningful Use Stage 2 requirements.
    - Query/Response is a query with automated response similar to current prescription history requests or patient eligibility checking. The challenges include that there are no national standards yet identified for this process. An incremental response may be the best method to keep objectives and outcomes aligned with standards that will emerge at a national level. Legacy standards wouldn't be best approach to address query/ response as the technology develops.
    - An option to add to this list is a manual response, to a specific query, which simply lists a telephone or fax number in order to contact the institution which has patient information to share. This could serve as an interim solution.
- The steps to locate a patient's record could be initially separated from the action to request and retrieve the record. This division could allow organizations to identify their best solution to respond to a record request/retrieve and for processes and standards to emerge. An

emergency department request for patient data can be identified as an emergency release of patient data regardless of permission to view the data (consent). (Slide 13)

- The group reviewed the specific questions included in the meeting materials. In general, the approach to Phase 2 appears to be reasonable and achievable. All agreed there are many issues to address. Specific questions and issues are noted at the beginning of these minutes. (Slide 16)
    - Comment: A list of advantages/disadvantages regarding the different components of Phase 2 would be helpful. This would help define the benefits and challenges for consumers and help the consumers to make decisions about consent.
    - Comment: Consumers should have a readily available list of organizations who participate in the HIway. This will allow consumers to make informed decisions when choosing healthcare organizations with regard to how the consumers' health information can be shared with other entities who provide healthcare to that consumer.
    - Question: Does the patient consent dictate whether that patient becomes part of the MPI?
    - Comment: There was a repeated suggestion to have consumer representation on the new HIT Council. This suggestion will become part of the next HIT Council agenda recommendation.

Next Steps

- Key points and recommendations will be synthesized and provided back to Advisory Group for final comments.
- Presentation materials and meeting notes will be posted to EOHHS website.
- A poll will be generated via email to determine a regular meeting time for the Advisory Group.
- The next HIT Council – March 13, 2013, 3:30-5:00 One Ashburton Place, 11th Floor, Matta Conference Room